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## End of Life Care in Canada: A Report from the Canadian Academy of Health Sciences Forum

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In Ottawa on September 20, 2012, the Canadian Academy of Health Sciences held a forum entitled, 'End of Life Care: the Last 100 Days'. Following an opening plenary by Dr. Daren Heyland, presentations and discussions ensued, highlighting recent research, current controversies, and future directions to improve end-of-life care in Canada [1]. Three articles in this issue of *Clinical Investigative Medicine* build on presentations from that day.

Since the beginning of time, birth and death have been the only two universal human experiences. We have expended much energy to improve the birth experience, but have yet to match efforts to improve the quality of dying. There is ample evidence of a gap between optimal care at the end of life, and what patients actually receive. One problem is inadequate communication. In an observational cohort of 1193 patients alive 4 months after receiving chemotherapy for newly diagnosed metastatic cancer, 69% of patients with lung cancer and 81% with colorectal cancer did not understand that chemotherapy was not likely to be curative [2]. Such misinformation clearly compromises patients' ability to make informed treatment decisions that are consonant with their preferences.

The majority of decedents are elderly patients who die from non-cancer related causes. There are several different 'dying trajectories' – each with different associated health care needs. As the population ages, more and more Canadians will live to develop and die with, or from, chronic illnesses. The focus of one article in this trio, chronic obstructive pulmonary disease (COPD), is a prototypical chronic condition characterized by periodic exacerbations and a relentless decline in lung function and impaired quality of life. Our traditional biomedical approach often fails patients with COPD - at huge cost to patients, families and the health care system [3].

The *matter* of dying and the *manner* of the dying process exact an enormous toll not only on the patient, but also on attendant loved ones. While most Canadians die in institutions, technologically supported [4], dying at home is often desired, albeit sometimes idealized. Family caregivers are non-paid family members (i.e. spouses and extended family members) of dying persons, who are typically both satisfied and stressed in their role. Burdens beyond the patient must be understood, particularly for patients dying at home. The second article in this trio highlights these poorly understood issues [5].

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Due to the availability of and reverence for medical technology today, not recognizing when dying begins and death is likely to occur often results in life-prolonging treatments right up until death. Some of these are unwanted or unwelcome. There is an urgent need to align care received with care desired at the end-of-life, given the change in demographics to an ever-increasing elderly population living with chronic illnesses. More effective advanced care planning, and a wider range of end-of-life care settings (e.g. hospice care) may help. Evidence informing the Canadian landscape as well as challenges and opportunities for our healthcare resources are provided in the third article in this trio [6].

A Senate Subcommittee Report on Palliative Care called 'Quality End of Life Care: The Right of Every Canadian' [7] brought these issues to light in 2000. Making palliative care a federal rather than provincial mandate may help to raise the bar and equalize options for citizens from coast to coast. Research that can change practice and policy is overdue. Acting on such research findings is critical. While many of today's healthcare efforts are population-based, an individualized approach to end-of-life care acknowledges that the dying person and their family members are uniquely human. If we needed a cause to unite us all, improving end of life care should be that cause.

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